

**Montgomery County  
Commission on Aging**

**STAKEHOLDER FORUM  
“FAMILY CAREGIVER SUPPORT: A DIALOGUE”**

**October 28, 2015**

**FINAL REPORT**

**STAKEHOLDER FORUM**  
**“FAMILY CAREGIVER SUPPORT: A DIALOGUE”**  
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## **EXECUTIVE SUMMARY**

Four out of every 10 adults in the United States care for relatives with disabilities or chronic illnesses. This number will continue to increase due to better healthcare and medical advances resulting in an extended life expectancy.

Last year the Montgomery County Commission on Aging (COA) conducted its Stakeholder Forum “Family Caregivers of Older Adults”. It was attended by 105 individuals including family caregivers, service providers, representatives of advocacy groups and disease specific organizations. Participants discussed the many challenges facing family caregivers in Montgomery County and brainstormed recommendations.

This year’s COA Stakeholder Forum, “Family Caregiving Support: A Dialogue”, held on October 28, 2015, discussed approaches to implement the recommendations made at last year’s forum and identified new and better approaches which may not have been considered.

The Forum was attended by 87 people. Similar to the 2014 Forum, the attendees represented family caregivers, service providers, representatives of advocacy groups and disease specific organizations.

The Forum was conducted in a panel format with a moderator. The moderator was a respected expert who had many years of experience in the family caregiver arena in direct service, research and policy. Panel one was composed of six County Council members and Maryland State legislators. Panel two was composed of six representatives of service providers, advocacy organizations and the business community.

Each panelist was given questions ahead of time that were relevant to their area of expertise. They were allowed five minutes for their responses. After each panel’s presentations the audience was given an opportunity to ask questions and make comments. The panelists’ presentations were comprehensive, specific, and very informative. Audience participation in terms of questions and comments was quite perceptive and elicited further specific information from the panelists.

The information from the panelists combined with the commentary from the mixed backgrounds of audience members led to the development of recommendations.

There were 16 recommendations and were grouped by Advocacy, Collaboration, and Legislation. These recommendations will be presented to the Director of the Montgomery County Department of Health and Human Services, the Montgomery County Executive and the Montgomery County Council. The County Caregiver Coordinator, when hired, should work on implementation plans for these recommendations:

### **Advocacy**

1. COA should advocate that the County Council and the County Executive promote to the Montgomery County State Delegation to the Maryland Legislature, support for passage of the CARE Act.
2. COA should advocate to the County Council and the County Executive to support private agencies providing private caregivers to families to have definitive standards for training these caregivers so they are proficient in the care they are contracted to provide and have adequate communication skills so they can effectively communicate with the families they serve.
3. COA should advocate that the Maryland delegation to Congress become members of the Congressional Caregiving Caucus and work toward a national strategy for the national challenge of family caregiving.
4. COA should advocate to the County Council and County Executive to support the conversion of the half-time County Caregiver Coordinator position to a full time position.
5. COA should advocate to the County Council and the County Executive to support additional funding for the County Village Coordinator and associated activities.

6. COA should advocate to the County Council and County Executive to support a comprehensive and coordinated effort to get information on family caregiver services to isolated and diverse communities.
7. COA should advocate to the County Council and County Executive to support a coordinated effort to make available information on long-term care insurance.
8. COA should advocate to the County Council and the County Executive to support the establishment of a private-public County Caregiver Coalition to coordinate the delivery of family caregiver services in the County and educate the public about these services.

## **Collaboration**

1. COA should encourage family caregiver service organizations to seek creative public-private partnerships.
2. COA, the County Council, and the County Executive should encourage local Chambers of Commerce and the business community to support and help employed family caregivers.
3. COA should collaborate with the County Council once the County Mental Health Inventory is completed to help identify gaps in mental health services and next steps to complement the availability of mental health services to family caregivers' loved ones.
4. COA encourages the collaboration of the County's State Delegation with the State Hospital Association to reach a compromise on making the CARE Act effective and acceptable and passable as legislation.
5. COA encourages creative collaboration of family caregiver service organizations, public agencies providing family caregiver services with Federal agencies that have responsibilities related to family caregiving that could result in innovative pilot projects.

## **Legislation**

1. COA should encourage the Maryland Congressional delegation to support Maryland Senator Barbara Mikulski's proposed legislation, the RAISE Act, to bring together Federal Agencies to provide a national strategy on family caregiving.
2. COA Public Policy Committee should study the feasibility of tax credits for the payment of long term care insurance.
3. COA Public Policy Committee should study the feasibility of offering tax credits to families who pay for the services of private caregivers.

## **BACKGROUND**

### Stakeholder Forum Goals

The Commission on Aging (COA) of Montgomery County (MC), Maryland serves as an advocate for the health, safety and well-being of the County's older residents and makes recommendations to the County Executive, the County Council, and the Maryland State Legislature on their behalf. COA supports both safety net services for the frail elderly as well as programs for vital older adults who want to age within their communities. COA's Senior Agenda was adopted by the County Executive and the County Council in 2012. The Senior Agenda provides priorities the County must focus on in order to become a community for a lifetime, a place for older adults to live safe, healthy and vital lives. Caregiver support is listed as a priority in the Senior Agenda's section on Health and Wellness.

COA's Annual Stakeholders Forum is one of the ways COA addresses significant issues and gets input and feedback from members of the public, organizations with a similar mission, and elected officials. This year's forum was held on Thursday, October 28, 2015, 8:30am - 12 noon, at the Silver Spring Civic Building, Silver Spring, MD. The Forum brought together legislators, non-profit organizations, businesses and family caregivers to explore possible solutions and make recommendations to assist family caregivers in Montgomery County.

The impetus and decision to focus the last two Stakeholder Forums on caregiving was derived from COA Summer Studies in 2014 and 2015. The 2014 COA Summer Study was on "Caregiver Services and Support in Montgomery County." The 2014 Stakeholder Forum focused on Family Caregivers of Older Adults and its goals were to:

- (1) Gather additional information about family caregiver concerns and issues
- (2) Consider gaps and challenges stated by the family caregivers
- (3) Provide the attendees with information about county services and supports available to family caregivers, from county experts

- (4) Review and evaluate the information from the stakeholder forum and identify areas that could enhance the services and supports available to Montgomery County's family caregivers.
- (5) Advocate for the needs of family caregivers to the County Executive and County Council.

The 2015 COA Summer Study was on "Long Term Care Services and Supports: Nursing Home Quality" and its goal was to educate Commissioners about the challenges surrounding the measurement and provision of quality care (note: 533 oversight regulations) in nursing homes in Montgomery County, and opportunities to enhance that care.

This year's Stakeholder Forum was to develop solutions to the needs of family caregivers including at a minimum the:

- a) coordination of caregiver services
- b) support for a State Council on Caregiving
- c) approaches to providing paid or safe leave (unpaid leave without fear of losing a job) to family caregivers
- d) availability, accessibility and expansion of information on essential programs, products and services
- e) consideration of the establishment of a public-private County-wide coalition of family caregiver services
- f) Identification of a variety of specific approaches to deliver crucial support.

### Stakeholder Forum Task Group

The COA Stakeholder Forum Task Group (Task Group) was led by Commissioners Spencer Schron and Grace Whipple. Other members on the Task Force included Commissioners: Myrna Cooperstein, Noelle Heyman, John Honig, Arva Jackson, Judith Levy, Barbara Multz, Isabelle Schoenfeld, Revathi Vikram and members of the public- Elinor Ginzler (Moderator), Sarah Gotbaum, Beth Shapiro, Susan Wranik and Odile Brunetto, Director of Area Agency on Aging.



## FORUM

### Introductory Remarks

#### **Judith Levy, Chairperson, Montgomery County Commission on Aging (COA)**

Judy Levy thanked COA's Task Force on Stakeholder Forum Planning for their extensive efforts in planning and conducting this significant event and second consecutive session on family caregiving. These efforts contributed greatly in focusing the County's efforts on family caregiving and supporting Montgomery County as a 'Community for a Lifetime'.

The COA has recognized the challenges in family caregiving and has conducted a summer study in 2013, a Stakeholder Caregiver Forum in 2014, a Summer Study in 2014, and extensive work in the COA Health and Wellness Committee on family caregiving.

The 2013 Summer Study identified the relevant legislation, resources, and issues in family caregiving. The 2014 Stakeholders Forum "Family Caregivers of Older Adults" made the following recommendations:

1. Coordination/organization/leadership of family caregiving services in the public, private, and voluntary sectors by a County entity.
2. Clarification and centralization of information in multiple languages.
3. Improved availability of respite care services.
4. Power of Attorney consistency.
5. Availability of mental health services.

The 2014 COA Summer Study reinforced the recommendations of the 2014 Stakeholders Forum, identified best practices, and recognized challenges to provide support. It also recommended a single point of contact for caregivers. The findings were:

1. No one size fits all.
2. There are varied approaches.
3. New technology is challenging.
4. Long distance caregiving is difficult.
5. There is need for a public-private coalition.
6. Local hospitals can do more in addressing caregivers' concerns.

7. There is need for creative public-private partnerships in the caregiving arena.

***Since then, a single point of contact, a County Caregiver Coordinator, has been approved by the Council.***

**Uma Ahluwalia, Director, Montgomery County Department of Health and Human Services**

Uma Ahluwalia announced that there will be a County Summit on Aging on December 3, 2015, sponsored by the County Executive which will continue the family caregiving conversation.

She stated that it was laudable that the COA had recognized family caregiving as a priority and has done admirable work in that area. She also stated that every year there was considerable testimony in budget community hearings about the need to take care of seniors and there was always poignant testimony about seniors needing caregiving and services. The annual issue in the budget hearings is “What does it take to support seniors?”, i.e. senior economy.

Ms. Ahluwalia quoted Mrs. Rosalyn Carter about caregivers:

“There are four kinds of caregivers: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregiving.”

She announced that the position of County Caregiver Coordinator is finally being filled per the COA recommendation just like the COA recommendations for County Transportation Coordinator and County Village Coordinator. The latter two hired Coordinators have contributed significantly to helping County seniors.

**Dorinda Adams, Senior Staff to the Maryland Caregivers Support Coordinating Council**

Dorinda Adams stated that she is the Director and provides support to the Maryland Caregivers Support Coordinating Council. The Council consists of 17 members, appointed by the governor. Delegate Marilyn Goldwater cosponsored the Council Law with Mr. Frosh, the Attorney General, and was active in

advocating its passage. The Council has been successful in advocating and generating public-private partnerships and hearing from family caregivers.

The Council conducted a family caregiving survey in 2014-2015. More than 2,700 people used the provided link. The survey was pushed out through Council partners including faith groups, non-profit groups, veteran organizations, business partners, and other sectors. The survey was also translated into Spanish. A hard copy of the survey is available.

The survey showed that the typical Maryland caregiver taking care of someone 60 or older was usually female and over 50 years of age. This shows an aging of this cohort since in 2002 when the typical Maryland caregiver was female and about 46 years old. The three most cited reasons for the caregiving were dementia, mobility issues, and developmental disabilities.

Detailed maps were produced illustrating various findings. These maps have been shared with COA. All 24 Maryland jurisdictions were surveyed. Montgomery County was tied with Baltimore County for the most responses provided. The most significant finding was that caregivers needed a break and needed to embrace all areas of life.

Dorinda Adams urged that the survey data be used to apply for grants since the data was county specific. The data should also be used for strategic planning. She emphasized that the Council was available for presentations using the data. She stated that no group should be overlooked in pursuit of public-private partnerships.

There are four Maryland Agencies partnering with the Council: Department of Aging, Department of Health and Mental Hygiene, Department of Human Resources, and the Department of Disabilities.

One use of the survey data is to make sure the Council is supported by these four Maryland State Departments. The Council is seeking long lasting partnerships and is trying to be innovative in seeking out these partnerships.

## **Elinor Ginzler, Moderator**

Elinor Ginzler introduced herself as the Moderator of the Forum. She explained that there was a lot to do in a short period of time. She stated that caregiving pervades all issues and everyone is impacted. There is no one solution.

She explained that there will be two panels. The first panel will be the public sector panel. The second panel will be composed of representatives of the business community, providers of caregiver services, and advocacy groups. Each panelist had been provided with questions ahead of time. Each panelist will be provided five minutes to respond to their respective questions. We will have an opportunity at the end of each panel to have questions and comments from the audience.

## **PANEL #1-COUNTY AND STATE LEGISLATORS**

### **Roger Berliner, Councilmember**

#### **Questions:**

Given the County's concerns for family caregivers, how can the County contribute to the implementation of last year's recommendations?

What legislation at the State and County levels related to family caregiving did you support but was not passed? Why?

#### **Answer:**

The senior population is a tsunami. It is supposed to increase by 17 percent in the next two years. There are many people who spend more than 40 hours per week taking care of their loved ones. The issue is, how can Montgomery County help create a community for a lifetime? I have a 92 year old mother in California who I am going to visit because she does not have many visitors. Family caregiving is not an option but an obligation.

There is need for a coordinator or ombudsman to identify and clarify the complex array of caregiver services. There is a need for help with navigating these services. The recently posted County position for a half-time Caregiver Coordinator should be a full time position.

The County Council passed the COA sponsored Senior Agenda. This document needs to be translated into action in its many facets. But, it must be realized that it is difficult time for budgets. I hope the budget that the Council receives from the County Executive reflects filling the needs of the Senior Agenda and caregiver needs.

I think we need partnerships with hospitals which are being required to deal with communities by legislation. Hospitals have to be engaged. We have to partner with hospitals to develop community plans. We have to take care of our loved ones where they are so they do not end up in the hospital.

Workforce development is needed in that there is a shortage of well-trained qualified private caregivers. There are not enough trained caregivers in the pipeline. We need trained people to provide quality care to seniors in need.

The developing villages around the County foster the concept that by helping one another, people will be able to stay in their own homes and age in place.

We need advice from the community. We have to learn how to reach isolated immigrant communities. We need to develop diverse approaches to these communities. There are existing models, such as the Alzheimer model, that are working and we need to identify and learn from them.

**Bonnie Cullison, Delegate**

**Questions:**

Given the County's concern for family caregivers, what Council initiatives can be taken to help family caregivers in Montgomery County?

What legislation at the State and County levels related to family caregiving did you support but was not passed? Why?

What issues and challenges are identified in passing of the CARE Act and how do you think they can be resolved?

**Answer:**

I think of myself as an older adult. I would like to recognize Delegate Ben Kramer in the audience who has worked long and hard on a variety of issue impacting seniors in the County.

Montgomery County is addressing these issues and sets the standard. The community sometimes does not know what is available. The County Council should help coordinate caregiver services and help make information accessible. I agree with the need for a full time County Caregiver Coordinator. I have cosponsored HB 1006 and am the primary sponsor of HB72 to have a designated month to focus on Alzheimer's disease and have programs and activities to address the needs of caregivers. This bill did not pass.

The CARE Act did not pass because it required hospitals to identify caregivers and provide them with care plans for their loved ones prior to discharge. The hospitals did not support this bill. The hospitals did not see the need to provide this service. I will work with Senator Kelley and try to develop a framework and set minimum standards for hospitals and their relationship with caregivers. It is important to realize that "one size does not fit all".

**Bernice Hutchison, Assistant to Secretary Kramer, State Agency on Aging****Questions:**

How can public-private partnerships be facilitated at the State and County levels?

Can the County Council work with the State to initiate a pilot program streamlining the County respite care program and expand it with no additional funds requested at this time of budgetary constraints?

**Answer:**

COA has done an amazing job!

Public-private partnerships are very important. COA and the County must continue to map assets. Leave no stone unturned. It is necessary to look vertically as well as horizontally for partners. Start with the respite care program

which has both State and County support. There are opportunities to streamline the respite care program.

It is necessary to look for champions who are catalysts for change. People are in strategic places who can help facilitate change. Legislative advocacy is an opportunity. Stakeholders are very important. Look at flourishing villages for potential help. Incubators for change can be found in partnerships. Look to hospitals. Look at the VA and mental health organizations for partnerships.

Ethnic diversity must not be overlooked. Diversity can drive funding. Follow the money, e.g. Weinberg Foundation. Do not overlook unfunded partnerships. Partnerships can provide necessary high end training.

Line up stakeholders and champions and look for opportunities for funding. The County Council can work with the State regarding streamlining of respite care programs. Think about triage in respite care, e.g. good working model in Westchester, New York.

Build a workforce around retired professionals.

### **Delores Kelley, Senator**

#### **Questions:**

What legislation at the State level related to family caregiving did you support but did not get passed and why?

What can you share about the State Task Force on Family Caregiving and what was learned?

What issues and challenges are identified in passing of the CARE Act and how do you think they can be resolved?

#### **Answer:**

The hospitals opposed the CARE Act. The Act required that a care plan be prepared for each discharged patient and was to be given to the caregiver at the time of discharge. There was no requirement that a family caregiver be identified while the patient was in the hospital to be trained in the necessary

caregiving techniques. If the caregiver could not be identified the hospital would have no liability. There are various ways a caregiver could be trained effectively, e.g. webinar, film.

Delegate Cullison and I will be meeting with the State Hospital Association to discuss a possible pilot program to show how the caregiver could be identified in a timely fashion and trained adequately before discharge to care for the patient upon discharge. If this is successful we can then try it statewide.

I have also been successful in getting the Maryland State Task Force on Caregiving Support to be staffed by AARP personnel.

There are 770,000 caregivers in Maryland and we will work on bills to keep our loved ones at home.

**George Leventhal, Council Chairperson**

**Questions:**

Given the County's concern for family caregivers, how can the County contribute to the implementation of last year's recommendations?

What legislation at the County and State level did you support but did not get passed? Why?

**Answers:**

The Sick Safe Paid Leave Act affects every employer in Montgomery County. It is needed statewide and nationwide. It must protect workers.

I too am a caregiver and recently flew to Los Angeles to help my grandmother.

We definitely need a better model for Power of Attorney to help represent our loved ones as well as protect them.

COA is one of the most effective advisory groups among the 80 plus advisory groups in the County.

We need an active partnership between the County and the State of Maryland.



There definitely is a need in the County for partnerships to help caregivers. The request to convert the recently approved half time County Caregiver Coordinator position to full time and the request for a modest amount of funds to help villages operate will be addressed in the upcoming budget.

Thank you for this opportunity to participate in your Forum.

**Jeffrey Myers, Assistant Attorney General**

**Questions:**

While consumers would like to purchase long term care policies, payouts are often in the very distant future. As a result consumers hesitate to buy policies fearing that the insurance companies may not be in business when the policies need to pay out. What protections are in place to:

- a. Protect consumers and
- b. Ensure that companies offering long term care will pay these claims when claims are made—possibly decades from the time of purchase.

Given the growing number of older adults using private caregivers, what thought, if any, has been given to educate the public as to what they need to know before engaging private caregivers (i.e. are they independent contractors or employees; the possible need for workers comp, ascertaining certification, first aid training, elder financial abuse, etc.) as well as the risks/rewards between hiring an agency caregiver and a private caregiver.

Has the Attorney General's office considered a consumer awareness education outreach program to educate the public on:

- a. the need to consider long term care insurance
- b. home healthcare aides: comparing public and private aides?

**Answer:**

The National Association of Insurance Commissioners has a booklet, "Long Term Care Shoppers' Guide", on its website that helps shopping for long term care insurance. It describes how to check on the financial stability of long term care insurance companies. This website also lists those long term care insurance companies which are authorized to sell long term care insurance in Maryland.

Maryland also has an insurance guaranty fund to back up insurance companies that may go bankrupt. The Maryland Health Care Commission also has information on long term care insurance. The Administration on Community Living (formerly the Administration on Aging) also has good information on long term care insurance.

Regarding hiring private caregivers:

1. Check information on the Internet.
2. The Family Caregiver Alliance has good information on hiring private caregivers.
3. The local Area Agency on Aging has good information on hiring private caregivers.
4. Maryland ACCESS website has a list of Medicaid approved agencies with private caregivers.
5. The Maryland Office of Health Care Quality has very good information regarding the hiring of private caregivers.
6. Make certain the nurse they send is licensed.

### **Questions/Comments from Audience:**

#### **Question:**

Appreciate the many aspects of caregiving covered by the panel. Many private caregivers do not speak or understand English. Many private caregivers are inadequately trained. Private caregiver companies have to do a better job of training people serving as private caregivers. Hospitals should do a better job of identifying family caregivers. The CARE Act should be passed. Families paying for private caregivers should receive tax credits. Is there any financial assistance available for the purchase of long term care insurance?

#### **Answer:**

Maryland limits long term care insurance companies to 15 percent increases. Some states have no limits. You can negotiate with a long term care insurance company that raises your premium by offering to reduce or modify services offered if increase is not affordable.

**Comment:**

Consideration should be given to a FICA like deduction to pay for long term care insurance so you start saving at a young age to self-insure.

**Comment:**

Seventy-three dollars per day is not adequate payment for a Medicaid waiver facility.

**Question:**

Why are hospitals opposed to CARE Act? The concept would lead to reduced readmissions, correct?

**Answer:**

Hospitals do not want to be directed by external organizations as to what to do when there is a liability issue.

**Question:**

Is there any legislation dealing with mental health supports?

**Answer:**

There is a hearing on November 16, 3-5 PM in Annapolis on mental health issues.

The County Council has a Behavioral Health perspective and has initiated a Behavioral Health Task Force in Montgomery County to inventory resources to identify gaps in Behavioral Health services. This effort is linked to the Committee on Oversight of the County Council.

**PANEL #2 - PROVIDERS, ADVOCATES, BUSINESS COMMUNITY**

**Lynn Friss Feinberg, AARP Senior Strategic Policy Advisor, Independent Living/Long Term Care**

**Question:**

From a national perspective what advice and strategies can you give family caregivers on new approaches and services for family caregivers?

**Answer:**

Family caregivers are the least appreciated and the most important in caring for our loved ones. I applaud Montgomery County for all their efforts to help family caregivers.

There are over 40 million family caregivers in our country. We have three quarters of a million caregivers in Montgomery County. The trend is now that more men are getting involved in family caregiving, not just women. Sixty percent of caregivers are working men and women which makes it difficult for these caregivers to provide proper care.

There is a tremendous unpaid contribution to the workforce by these family caregivers. The economic value of caregiving provided by family caregivers in the U.S. is \$470 billion. In Montgomery County the economic value of family caregiving is \$9.4 billion.

There are now many new evidence based programs that are highlighting services to build skills to solve problems. Family caregivers are not taking advantage of them.

Do as you are doing and speak out.

Telehealth is important and playing an increasing role. Family caregivers must improve their own health.

Eighteen states have passed a version of the CARE Act.

There is now a Congressional Caucus on Caregiving in Congress, but there are no representatives from Maryland on the Caucus.

Senator Barbara Mikulski is working on legislation to create a national strategy for caregivers that will speak to involvement of business and government. This RAISE Act is a strategy to support caregivers to include rolling out services and programs for caregivers.

**Elisa Kerneklian, Director of Human Resources, TW Perry**

**Questions:**

Would you share the impact of family caregiving on your employees and on your business?

Would your business consider partnering with other businesses and public and private organizations that advocate for/or provide family caregiving services?

**Answer:**

Our company has a “family feel”. We try to reduce the stress of family caregiving by giving time off, providing financial or moral assistance, arranging for referrals, stretching workload over other employees wherever possible, hire temporary help, and help caregiving employees wherever possible. The family caregiver/employee will appreciate these efforts in his/her behalf and be a better and more loyal and productive employee. The employer benefits by reduced turnover, higher retention, reduced recruitment and training costs for new employees.

We have worked with a local cancer organization to get information to employees so they could be better informed of the disease and they were encouraged to share that information with their families and friends. This information would help them be better informed about early screening and seeking of treatment if necessary.

**Susy Elder Murphy, Debra Ley Elder Care Associates, Owner**

**Question:**

When the family caregiving crisis initially occurs what should the new family caregiver do in order to respond to the crisis and begin to set out a plan?

**Answer:**

“When you are inside the jar, you cannot read the label”. The family caregiver has to reach out to someone who is not in the jar to see long term and short term plans, and figure out solutions that best serves the client.

The new family caregiver should reach out to someone outside the home to help strategize, e.g. hotline, family member, geriatric care manager/aging lifecare

professional. It is necessary to examine the physical, mental, and financial aspects of the caregiver issue presents, and develop a long term plan. Take full inventory of the problem and develop a long range plan. Some caregiver problems are long term some are short term. Family caregiving is not a sprint but a marathon. It will be necessary to consider putting together a team to deal with the various aspects of the family caregiving crisis.

We need to support the family caregivers because it takes a village to provide help.

**Tom Najjar, Founder/President Care Plus Incorporated**

**Questions:**

How does a family caregiver determine what sort of help is needed in the home and what are the priorities to be considered?

Is there any form of financial assistance to help defray the costs of in-home caregiver help?

**Answer:**

Look for signs of neglect in routines, neglect of the house, spoiled food, unusual behavior patterns, frequent falls, frequent UTIs, calls in the middle of the night, dirty laundry, illnesses that cause a hospital visit, old or spoiled food in the refrigerator. Look for someone who can give assistance and professional guidance. Arrange for a home evaluation and conduct a financial analysis. Look into life insurance conversion, annuities, VA benefits, check with Montgomery County Area Agency on Aging and Aging and Disability regarding services and benefits and possible State assistance available for seniors, and do not recommend a reverse mortgage, which should be a last resort.

**Lindsey Vajpeyi, Alzheimer's Association, Program and Services**

**Questions:**

What aspects of family caregiving challenges have answers in technological approaches such as monitoring, access, telework? Which?

What aspects of family caregiving issues present an opportunity for a Federal role and approach? Which?

**Answer:**

You must consider if the technology being considered matches the patient's needs and resources. Is the technology really useful for the need? What are the ethical considerations?

Physical safety is very important with technology. Consider GPS devices, medication reminders, emergency response systems, but also include considerations for comfort and quality of life, e.g. remotes, I-Pods.

Technology can also be helpful for the caregiver, e.g. smartphone, smartphone apps for meditation, ordering groceries, telework. These technological assists must meet the needs of the person using them.

There has been legislation introduced in Congress to help caregivers. The HOPE Act was introduced to provide Medicare coverage to educate providers. The Care Planning Act of 2015 was introduced in Congress to provide services for progressive diseases.

**Susan Wranik, Chair, Intergenerational Resource Group, Bethesda-Chevy Chase Chamber of Commerce**

**Questions:**

Do you find that your Chamber members are aware of the cost of family caregiving to their companies' bottom line and to employed caregivers individually as well?

What family caregiving benefits do your Chamber members offer their employees?

**Answer:**

No, the Chamber members do not understand the cost of family caregiving. Seventy five percent of employees will be or are currently caregivers. Everyone is affected by caregiving. "Presenteeism" is the condition of being present at work but being distracted and stressed by family caregiving issues.

The Bethesda-Chevy Chase Chamber of Commerce is the only group with an intergenerational group. This group recognizes that family caregiving impacts all

ages. Family caregiving is a very difficult problem. People do not know what they need to know about family caregiving and do not want to find out until it is an emergency.

The Family Medical Leave Act and the Earned Sick and Safe Leave Act both represent a cost. What is the impact of the costs on employers? These costs will ultimately be passed onto the consumers.

There is a pro bono legal model where legal services are offered to those in need of professional legal help for no cost by legal professionals as part of their overall professional work. We need a similar model for health care professionals where people can be referred to health care professionals for health care with no costs as part of their routine provision of health care to the community.

The Government should consider a 211 line, like the emergency lines, to contact health care professionals.

#### **Questions/Comments from Audience:**

##### **Question:**

Bills are passed but unknown by the public. If a person is unable to operate in their apartment can they break their lease? If workers are overworked or don't have the tools, who is supposed to go to their home and assess their needs?

##### **Answer:**

There is a need to educate, advocate, legislate, educate.

##### **Question:**

Regarding the CARE Act, discharge planners are opposed to the passage of this act, yet patients are being readmitted to hospitals because caregivers are not included in preparing properly for the discharge of the patients which may reduce these readmissions. The act only requires caregivers to be designated but does not determine whether they are able or trained to do the job.

##### **Answer:**

There is no doubt that inclusion of caregivers prior to discharge is necessary and will reduce readmissions.



**Comment:**

There are cultural differences that affect the care to be given. We need training of caregivers for different ethnological communities.

**Question:**

We have a fragmented system challenging family caregivers. What can be done?

**Answer:**

We need oversight of the services and system confronting the family caregivers.

**Comment:**

You can't separate health, transportation and housing considerations from care receivers needs.

**Comment:**

It would be useful to have certification for care for aging patients who understand the broad needs.

**Comment:**

The diversity of communities in Montgomery County presents barriers to obtaining family caregiver services and other help.

**Answer:**

Agree. Need substantial efforts in this area.

**Question:**

How can we work better with the Disability Community to help them get better services and help their caregivers?

**Answer:**

AARP's Public Policy Institute has been focusing on the Disability Community and has new and varied approaches dealing with the Disable Community. Check AARP website.

Maryland has programs dealing with the Disability Community. It is important to note that housing, health, and transportation are all integrated with issues facing caregivers generally and caregivers in the Disabled Community.

**Question:**

What prompted TW Perry to adopt such a supportive role with respect to its employees and caregiving issues?

**Answer:**

It was the right thing to do. It also definitely helps retention and obviously reduces recruitment costs. It hopefully leads to employee loyalty and possibly increased productivity although no research at TW Perry has been done on that.

**Question:**

Considering that there are so many Federal agencies headquartered in the local area what can be done to initiate some form of collaboration with them regarding family caregiver services, e.g. pilot project, or stimulate Federal agencies to work together on family caregiving?

**Answer:**

The RAISE Act introduced into Congress seeks to bring Federal agencies together to strategize about family caregiving.

## **DISCUSSION, RECOMMENDATIONS, NEXT STEPS**

### **DISCUSSION**

The Forum discussion was wide ranging and substantive. The panelists were specific in their responses to the prepared questions. The audience clearly understood points being made and was very familiar with the issues and challenges of family caregiving as reflected in their cogent questions.

A variety of excellent ideas were offered by panelists and audience participants that could be categorized into three main themes: Advocacy, Collaboration, and Legislation. Advocacy would be those ideas or initiatives that could best be supported by COA and communicated to the appropriate organizations to generate actions or results beneficial to family caregivers. Collaboration would be those ideas or initiatives that COA would urge certain organizations to pursue in a joint effort to bring about certain results that would be advantageous to family caregivers. Legislation would refer to those ideas that have potential to be legislative initiatives that if passed would help family caregivers.

### **RECOMMENDATIONS**

#### **Advocacy**

**1. COA should advocate that the County Council and the County Executive promote to the Montgomery County State Delegation to the Maryland Legislature, support for passage of the CARE Act.**

This Act should be rewritten with input from the State Hospital Association that would involve the family caregiver at an appropriate time in the hospitalization prior to discharge that would familiarize and train the caregiver in what steps are required to properly care for the patient after discharge to promote recovery, guarantee quality maintenance and overall contribute to quality care and avoid readmission to the hospital. The family caregiver should be an integral part of the discharge process.

**2. COA should advocate to the County Council and the County Executive to support private agencies providing private caregivers to families to have definitive standards for training these caregivers so they are proficient in the care they are contracted to provide and have adequate communication skills so they can effectively communicate with the families they serve.**

Many of the caregivers provided by private agencies to families in need of trained caregivers to help care for their loved ones are not trained in caring for sick, disabled, or otherwise impaired patients. Many do not speak fluent English or understand English thus making a difficult situation more complex and endangering the health of the patient. Minimum training standards should be created and adhered to so contract private caregivers can contribute helping the patients. Similarly, there is need for minimum standards of communication. The private caregiver should be expected to speak and understand English.

**3. COA should advocate that the Maryland delegation to Congress become members of the Congressional Caregiving Caucus and work toward a national strategy for the national challenge of family caregiving.**

Since there is a Caregiving Caucus in the U.S. Congress it would seem to be advisable to have the Maryland Congressional Delegation be members of this group to help strategize how to bring Federal agencies together to foster improved and new services for the increasing national issue of family caregiving.

**4. COA should advocate to the County Council and County Executive to support the conversion of the half-time County Caregiver Coordinator position to a full time position.**

The recently created position of half time County Caregiver Coordinator should be converted to a full time equivalent because the intended work to be accomplished by this individual is substantive and will require a considerable amount of time to be done properly. This individual will have as one of their major responsibilities the creation of a County Caregiver Coalition which in itself will require a substantial amount of dedicated time, not to mention the other ancillary responsibilities to be carried out by this individual.

**5. COA should advocate to the County Council and the County Executive to support additional funding for the County Village Coordinator and associated activities.**

This additional funding for the County Village Coordinator would be a relatively small sum of funds to help villages get started and operate. These funds would help with basic office supplies and associated operating costs. This relatively small sum of money would represent a small investment for larger returns and savings in the form of helping family caregivers help their loved ones to age in place and stay in their homes. Villages also help their members with various support services which help family caregivers.

**6. COA should advocate to the County Council and County Executive to support a comprehensive and coordinated effort to get information on family caregiver services to isolated and diverse communities.**

There are many isolated, remote, and diverse communities which are not aware of available information on family caregiver services provided by the County and other entities that would help these families assist their loved ones. A coordinated and comprehensive effort to get this information to these communities is necessary.

**7. COA should advocate to the County Council and County Executive to support a coordinated effort to make available information on long-term care insurance.**

There is a large amount of information available on long term care insurance at the State level at various State Agencies (Agency on Aging, Insurance Commission, Office of Health Care Quality), at the national level (e.g. National Association of Insurance Commissioners, AARP, Administration on Community Living formerly the Administration on Aging), and at the local level. Clarifying the mystique of long term care insurance may lead to more people purchasing long term care insurance which would help with home caregiving services later in life.

**8. COA should advocate to the County Council and the County Executive to support the establishment of a private-public County Caregiver Coalition to coordinate the delivery of family caregiver services in the County and educate the public about these services.**

There is a definite need for the creation of a centralized entity in the County that would bring together public and private family caregiver services to coordinate their efforts and communicate to the public their availability, fees, accessibility, requirements, and other facets of their operations.

## **Collaboration**

### **1. COA should encourage family caregiver service organizations to seek creative public-private partnerships.**

All public and private family caregiver related service organizations should try and seek creative and innovative partnerships to enhance their funding, expand service availability, increase staffing, and overall improve the quality of their offerings. They should consider the Veteran Affairs Department, the Weinberg Foundation, Schools of Social Work, Programs in Certified Nurse Assistants, and other non-traditional sources of assistance.

### **2. COA, the County Council, and the County Executive should encourage local Chambers of Commerce and the business community to support and help employed family caregivers.**

The financial impact of family caregiving on the employed family caregivers is substantial as well as on the employer. The employed family caregiver may lose opportunities for promotion, travel, and other employment enhancements due to the necessary time away from the office for doctors' appointments or other necessary functions to care for the loved one. The caregiver may have to quit work to care full time for the loved one thereby having reduced social security payments and obviously loss of income. The employer is impacted due to time off for the caregiver, distraction, preoccupation with phone calls concerning the loved one, and other factors. Being supportive of the employed family caregiver can result in increased productivity, increased loyalty, and ultimately retention thereby saving recruiting and training costs which can be substantial.

### **3. COA should collaborate with the County Council once the County Mental Health Inventory is completed to help identify gaps in mental health services and next steps to complement the availability of mental health services to family caregivers' loved ones.**

The COA's Committee on Health and Wellness has done extensive work in the mental health services area and could be helpful to the County in identifying strengths and weaknesses of the County's services and recommending how to constructively fill the gaps to provide a full complement of mental health services for County residents including family caregivers' loved ones.

**4. COA encourages the collaboration of the County's State Delegation with the State Hospital Association to reach a compromise on making the CARE Act effective and acceptable and passable as legislation.**

COA strongly supports the proposed meeting of County State legislators with the State Hospital Association to discuss facets of the CARE Act that could be modified and acceptable to all parties. This would lead to early identification of the family caregiver during the hospitalization and proper training of that person to care for their loved one after discharge, limited hospital liability, and reduced incidence of re-admissions.

**5. COA encourages creative collaboration of family caregiver service organizations, public agencies providing family caregiver services with Federal agencies that have responsibilities related to family caregiving that could result in innovative pilot projects.**

COA supports the collaboration between local caregiver provider organizations and Federal agencies regarding innovative ways to deliver, finance, or otherwise provide family caregiver services. Given the proximity of these Agencies to the County and the opportunity to be close to the actual proposed project it would seem to be conducive to explore these avenues. These projects would be conducted on a local basis and if successful could be expanded to statewide, and then if again successful on that basis may be a model for nationwide implementation. Federal agencies for consideration include the Department of Health and Human Services/Centers for Medicare and Medicaid Services and the Administration of Community Living (formerly the Administration on Aging).

## **Legislation**

**1. COA should encourage the Maryland Congressional delegation to support Maryland Senator Barbara Mikulski's proposed legislation, the RAISE Act, to**

**bring together Federal Agencies to provide a national strategy on family caregiving.**

This proposed legislation would help people recognize what they have to do with regard to family caregiving and how the various Government agencies could help.

**2. COA Public Policy Committee should study the feasibility of tax credits for the payment of long term care insurance.**

Long term care insurance could be an expensive purchase. If tax credits were offered in conjunction with this purchase long term care insurance may be more palatable to the public.

**3. COA Public Policy Committee should study the feasibility of offering tax credits to families who pay for the services of private caregivers.**

Paying for the services of private caregivers is expensive. Since family caregivers undertake these expenses which keep their loved ones at home and avoid nursing home stays and Medicaid payments for the remainder of their lives this would seem to be a good investment to avoid longer larger Government payments.

## **NEXT STEPS**

These recommendations should be presented to the Director of the County Department of Health and Human Services, the County Executive, and the County Council.

COA should work with the Maryland State Delegation, County DHHS Director, County Executive, and County Council to develop implementation plans for those recommendations that are supported. Once a County caregiver Coordinator is hired that person should be actively involved and be the lead on developing the implementation plans for these recommendations.



## APPENDIX B-1

COA STAKEHOLDER FORUM ATTENDEE LIST – OCTOBER 28, 2015	
PUBLIC	
Karen Berglund	Glickman Design Build
Teresa Boring	Debra Levy Eldercare
Carol Browne	
Janet Carter	Right at Home
Carol Cober	Friends House, Sandy Spring
Clifford Cohen	
Phyllis Courlander	Top Banana Home Delivery Groceries
Morton Davis	MCPD
Sue Dollins	Advanced Home Support
George Ezikpe	Firsts Light Home Care
Ryan Frederick	
Elinor Ginzler	Moderator – Jewish Council on the Aging
Sara Gotbaum	
Melvin Greberman	
Gail Gunod-Green	Housing Opportunities Commission
Jenna Stone Haley	Donna Kerr Group (Real Estate)
Henry Harris	Benjamin Gaither Center
Vivien Hsueh	
Deborah Juneja	Montgomery College
Lauren Kroger	
Meg LaPorte	
Nelson Leroy	
Jean Levin	Alfred House
Kate Lewis	Seabury Resources
Cindy Libby-Green	JSSA-Premier Homecare
Tabassum Majid	Univ. of MD-Baltimore
Mona Negm	
Lois Neuman	
Magnolia Paz	Holy Cross Hospital
Zalika Pierce	Holy Cross Hospital
Nargiza Polvanova	
Marcia Pruzan	
Andrea Rogers	
Hileia Seeger	
Marcy Smith	Holy Cross Hospital
Jenna Stone	
Marilee Tollefson	
Vincent Tung	
Lorrie Van Akkeren	
Joan Van De Moortel	Care For You-Executive Director
Detta Voesar	Susan Wranik Assoc.

Robin Walker	
Kristen Wheeden	Holy Cross Hospital
Kathleen Williams	Holy Cross Hospital

## APPENDIX B-2

COMMISSION ON AGING MEMBERS	
Myrna Cooperstein	
Stephanie Edelstein	
Morton Faller	
Sue Guenther	
Noelle Heyman	
John Honig	
Arva Jackson	
Chuck Kauffman	
Judy Levy	Speaker – Chairperson COA
Karen Maricheau	
Jerry Morenoff	
Barbara Mulitz	
Isabelle Schoenfeld	
Spence Schron	
Revathi Vikram	
Grace Whipple	
MONTGOMERY COUNTY GOVERNMENT PERSONNEL	
Uma Ahluwalia	Speaker – Dept. of Health & Human Services
Odile Brunetto	DHHS
Emily Glazer	DHHS
John (Jay) Kenney	DHHS
Leslie Marks	DHCA (Senior Fellow)
MONTGOMERY COUNTY COUNCIL	
Roger Berliner, Councilmember	Panelist
Warren Hansen	Berliner aide
George Leventhal, Councilmember	Panelist
Craig Rice, Councilmember	
MARYLAND STATE GOVERNMENT PERSONNEL AND LEGISLATORS	
Dorinda Adams	Speaker – Staff, MD Caregivers Support Coordinating Council
Dakota Burgess	MD Dept. of Transportation
Mary Collins	Frederick County Dept. of Aging (DOA)
Bonnie Cullison, Delegate	Panelist - MD State Delegate
Linda Forsyth	Chief of Staff, Senator Kelley
Bernice Hutchison	Panelist – Assistant to Secretary Kramer -MD DOA
Delores Kelley	Panelist – MD State Senator
Ben Kramer	MD State Delegate
Jeffrey Myers, MD Assist. Atty General	Panelist – Representing Atty. General Brian Frosh
Selena Singleton	
Terri Williams	MD Dept. of Aging
NON-GOVERNMENT PANELISTS	
Tammy Bresnahan	AARP MD
Lynn Feinberg	Senior Strategic Policy Advisor, AARP

Elisa Kerneklian	Director of Human Resources, T.W. Perry
Susy Elder Murphy	Owner, Debra Levy Elder Care Associates
Tom Najjar	Care Plus
Linsey Vajpeyi	Alzheimer's Assoc.
Susan Wranik	Chairperson, Intergenerational Resource Group, Bethesda-Chevy Chase Chamber of Commerce